

# Draft Technical Brief

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### Transition Care for Children With Special Health Needs

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None of the investigators has any affiliation or financial involvement that conflicts with the material presented in this report.
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## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome comments on this Technical Brief. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to [epc@ahrq.hhs.gov](mailto:epc@ahrq.hhs.gov).

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In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the technical brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The Task Order Officer and the Evidence-based Practice Center work to balance, manage, or mitigate any conflicts of interest.

The list of Key Informants who participated in developing this report follows:

**Peer Reviewers**

Prior to publication of the final evidence report, the EPC will seek input from independent Peer Reviewers without financial conflicts of interest.

# Structured Abstract

## Background

Around 500,000 children in the United States with special health care needs transition to adult care annually. Fewer than half receive adequate support and services for their transition to adult care, and the proportion is even lower for ethnic minorities and children living in poverty. Examples of programs with the potential to enhance transition for children with special health care needs include use of a separate transition clinic, engagement of a transition coordinator, and a phased transfer within a clinical system. The potential for these programs to be effective is offset by barriers to their implementation.

## Purpose

We developed a technical brief (rapid report) on the state of practice and the current literature around transition care for children with special health care needs to describe current practice, and to provide a framework for future research.

## Methods

We had conversations with Key Informants representing clinicians who provide transition care, pediatric and adult providers of services for individuals with special health care needs, policy experts, and researchers. We searched online sources for information about currently available programs and resources, and we conducted a literature search to identify currently available research on the effectiveness of focused transition programs.

## Findings

The issue of how to provide good transition care for children with special health care needs warrants further attention. The numbers of children with special health care needs reaching adulthood are increasing, and the diversity of their clinical conditions is expanding. The *Got Transition* resource provides a framework for transition care that can be adapted to serve the individual needs of a given patient population, but there is little evidence that it is used to provide a framework for evaluation in the research literature. Despite identifying numerous descriptions of existing transition programs or services, we identified only 21 evaluation studies, the majority of which did not include concurrent comparison groups. Most (n=8) were conducted in populations with diabetes, with a small literature (n=5) on transplant patients and no more than one study on each of a number of other conditions. Common components of care included use of a transition coordinator, a special clinic for young adults in transition and provision of educational materials, sometimes using computer-based programming.

An important consideration going forward is recognizing that transition care for chronic conditions like diabetes may warrant a different approach than care provided for more heterogeneous and complex conditions, particularly those that include a behavioral or intellectual component. Care for some patients may be appropriately provided in primary care at the community level, while for others, it may be appropriately provided only in highly specialized regional or academic centers.

Research needs are wide-ranging, including both substantive and methodologic concerns. At this point in time, the field lacks even a consistent and accepted way of measuring transition success, and it will be essential to establish consistent goals in order to build an adequate body of literature to affect practice.

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# Background

There is no uniformly accepted age at which pediatric care is inappropriate and adult care should be sought for every patient. Nonetheless, some practices do have age cut-offs, and there comes a time when adult providers may be better able to serve the needs of patients whose medical concerns are more adult in nature, including for example reproductive and other issues. In addition, the inclusion of adults in pediatric practices can create discomfort and challenges for other pediatric patients and their families, and pediatricians can find themselves addressing medical issues of adults for which they are less prepared. Therefore, at some point, most pediatric patients should and do move into the adult care system.

An effective transition process from a pediatric to an adult health system should ensure continuity of developmental and age-appropriate care. In 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) jointly published recommendations describing the purpose of transition care as to “maximize lifelong functioning and well-being...[thereby] ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.”<sup>1</sup>

This process can be challenging, particularly for children and youth with special health care needs (CSHCN), who are defined as having or being at risk of “a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>2</sup> Examples of adolescent populations with special health care needs that need transition support range widely, including those with chronic illnesses such as diabetes or sickle cell disease and individuals with developmental disabilities that are associated with a host of challenges ranging from higher risks of specific health outcomes to the need for special support in navigating the health care system.

Currently, around 500,000 children in the United States with special health care needs transition to adult care annually.<sup>3, 4</sup> Although they only represent an estimated 13 to 16 percent of all children, CSHCN account for as much as 70 percent of child health care expenditures,<sup>3, 5, 6</sup> and most of these individuals will survive into adulthood as the life expectancy of children with chronic illness has increased dramatically over the last 3 decades.<sup>7, 8</sup> Fewer than half of CSHCN report that they receive adequate support and services for their transition to adult care,<sup>9</sup> and the proportion is even lower for ethnic minorities and children living in poverty.<sup>10, 11</sup>

Examples of programs that have been proposed to enhance transition for CSHCN include use of a separate transition clinic, engagement of a transition coordinator, and a phased transfer within a clinical system.<sup>12-15</sup> The potential for these programs to be effective is offset by barriers that include a lack of time and resources to address transition issues, inadequate reimbursement, hesitancy of families and providers to dissolve long-standing therapeutic relationships, and gaps in residency training for both transition processes and medical management of adults with childhood-onset chronic diseases.<sup>16-19</sup> Additionally, CSHCN face broader challenges, including issues related to insurance, entitlements, guardianship, and eligibility for adult community-based services.<sup>2, 20</sup>

Nonetheless, several guidelines panels and other groups coalesce around the need for good transition care for this population in particular. Healthy People 2010<sup>21</sup> includes a goal that all young people with special health care needs receive the services needed to make necessary transitions to all aspects of adult life, including health care. The AAP states that “optimal health care is achieved when every person at every age receives health care that is medically and

developmentally appropriate.”<sup>4</sup> One of the six core objectives of the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) is that “all youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.”<sup>22</sup> Despite this consistency in intent, there is little evidence to date about what constitutes an effective transition program for this population of patients,<sup>23</sup> although a literature of program descriptions, evaluations and research on the topic is growing.

*Got Transition*,<sup>24</sup> a federally funded initiative, translates the six elements identified by the AAP, AAFP, and ACP in the 2002 consensus statement<sup>4</sup> and 2011 guidance<sup>1</sup> into actions, resources, and measures of quality available to pediatric and adult practices.<sup>25</sup> *Got Transition*<sup>24</sup> got transition is the most widely known and published standard approach to transition planning and process, and when asked about standard components of transition planning, the Key Informants on this project consistently pointed to this approach. Importantly, the initiative describes standard elements for inclusion, but allows for the elements to be designed and implemented in a targeted manner to match the specific needs of the clinical condition or health care system. Thus, while the standard underlying elements are consistent, the manner in which they are deployed is targeted and specific. We elected to use these elements as a framework for organizing this report and for assessing the literature base on transition care.

The Six Core Elements of Health Care Transition<sup>25</sup> outline parallel actions for pediatric and adult providers around six core concepts for successful transition care: policy, patient registry, preparation, planning, transfer, and completion. These components form the basis for development and implementation of projects to support transitioning youth. Notable initiatives include the National Health Care Transition Center multi-site learning collaborative which pilots the six core elements of transition, and the Center for Medical Home Transition which includes visits from nurse case manager and sharing of information.<sup>12</sup> The National Health Care Transition Center also developed an assessment tool for use in the empirical evaluation of transition programs.<sup>12, 25</sup> Nonetheless, the current body of literature is primarily descriptive with only few reports of effectiveness.

## Technical Brief Objectives

### Guiding Questions

We presented the following questions to the Key Informants:

#### Question 1. Description of interventions for transitions care

- a. What is the purpose of transition care and what are the theoretical advantages and disadvantages?
- b. What are the common components of transition care interventions or processes used in clinical practice for children/adolescents with special health care needs?
- c. How do currently used approaches to transitioning health care address the complexity of health issues including comorbidities and the presence of both physical and intellectual/developmental disabilities?

## Question 2. Description of the context for implementing transition care

- d. How widely available are programs or approaches to transition care within the health care setting for children/adolescents with special health care needs?
- e. What are the resources needed to implement transition care?
- f. What are the specific barriers to implementing transition care or processes for children/adolescents with special health care needs?
- g. Who delivers transition interventions and what training is required to implement identified approaches to transition care for children/adolescents with special health care needs?

## Question 3. Description of the existing evidence

- h. What patient groups/clinical conditions are represented in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- i. What is the length of followup in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- j. What outcomes are measured in studies on the use and evaluation of transition care for children/adolescents with special health care needs?

## Question 4. Issues and future research

- k. What are the implications (e.g., ethical, privacy, economic) of the current level of diffusion and of further diffusion of transition care for children/adolescents with special health care needs?
- l. What are possible areas of future research for transition care for children/adolescents with special health care needs and which research designs are most appropriate to address these research topics?

## **Methods**

We used discussions with Key Informants, a search of the grey literature, and a search of the published literature to collect relevant data and descriptions.

### **Data Collection**

#### **Discussions With Key Informants**

We searched the Web sites of relevant professional organizations and research and policy groups to identify stakeholders whose work or interests indicate a high likelihood of interest and expertise in the topic. In consultation with the investigative team and the Agency for Healthcare Research and Quality (AHRQ), we assembled a list of individuals representing a clinical, policy, research, or advocate perspective for transition care. Following approval by AHRQ of the completed Disclosure of Interest forms for proposed Key Informants, we conducted discussions with Key Informants. Discussion with Key Informants based on the guiding questions informed the content of Technical Brief. In particular, we asked informants about issues related to definitions, clinical areas, population, implementation, resources, and future research needs.

#### **Published Literature Search**

We used indexing terms and keywords to search the published literature for studies that evaluated programs. The definition of CSHCN is broad and may encompass many diagnoses and substantial heterogeneity in medical complexity. We used a combination of terms for specific chronic diseases (e.g., asthma) and disabilities (e.g., blindness), as well as broad terms (e.g., congenital defects) and descriptors of youth with special health needs and transition care (e.g., continuity of patient care). We limited the search to studies published in 2000 or later. The detailed search strategy with search results is presented in Appendix A.

An experienced library scientist vetted all search strategies and assisted in the selection of appropriate databases. We reviewed the reference lists of retrieved publications for other potentially relevant publications missed by the search strategies. The search will be updated while the draft brief is being reviewed to identify newly published relevant information. We will incorporate the results from the literature update into the Technical Brief before submission of the final report.

We used prespecified criteria to screen the search results for inclusion. We developed a simple categorization scheme for coding the reasons for exclusion from the report. We used EndNote® (Thomson Reuters, New York, NY) to record and track the disposition of references.

#### **Grey Literature Search**

Examples of sources of grey literature include the Internet, government Web sites, clinical trial databases, trade publications, and meeting abstracts. We conducted searches of databases that provide coverage of non-peer-reviewed literature (e.g., Lexis-Nexis®, ProQuest) and those that cover ongoing health services projects (e.g., NIH RePORTER, HSRProj, ClinicalTrials.gov), as model and project descriptions may appear in these resources. We

complemented this approach with searches of Web sites from relevant professional associations (e.g., the National Association for the Dually Diagnosed) and patient advocate groups (e.g., the Cystic Fibrosis Foundation) for the diseases and special needs covered.

## Data Organization and Presentation

### Information Management

We developed forms for screening and data collection (Appendix B) from the published literature. We recorded the study design and study populations from relevant sources. We focused on transition care from pediatric to adult services for individuals with chronic conditions. We did not limit by clinical condition, as a goal of this review was to identify common characteristics of effective transition support across clinical conditions. We limited by type of care, excluding studies of transition care in the context of palliative or hospice care.

We further limited the literature for Guiding Question 3 to original research studies. Table 1 summarizes the inclusion and exclusion criteria for the evaluation studies (i.e., those included in GQ3). We scanned the text of all included publications for information on barriers, training needs, variation in practice, and the potential impact of transition care on economic and policy decisions. We documented reasons for exclusion of records that were promoted for full text review. (Appendix D)

**Table 1. Inclusion and exclusion criteria for evaluation studies**

Category	Criteria
Study population	Children with special health care needs
Publication languages	English only
Admissible evidence (study design and other criteria)	<p><u>Admissible designs</u> Randomized controlled trials, including wait-list control, cohorts with comparison, pre-post cohort without comparison, stepped wedge designs, case-control, case series, and case reports</p> <p><u>Other criteria</u></p> <ul style="list-style-type: none"> <li>• Original research studies that provide sufficient detail regarding methods and results to enable use and adjustment of the data and results.</li> <li>• Studies must address the following for transitions in care: <ul style="list-style-type: none"> <li>○ Transitions of care from pediatric to adult services.</li> <li>○ Children with special health needs as defined by the American Academy of Pediatrics.</li> <li>○ A special health need that arises from a chronic physical, developmental, or intellectual condition or disability.</li> </ul> </li> </ul>

### Data Presentation

We summarize the Key Informant interviews and compile the information extracted from the published and grey literature. We organize the transition care components into categories and describe commonalities among existing transition care models or programs, as well as approaches that warrant further evaluation (Guiding Question 1). We identify resources for and barriers to adoption and implementation of transition care (Guiding Question 2). We present information on current practice and research in summary tables and text (Guiding Question 3). We highlight the implications of existing transition care practice and the need for future research in Guiding Question 4. We used grey literature sources to locate innovative transition care models and programs and present this information in tables in Appendix C. We also catalogued

information on transition care services from individual States and health care systems.  
(Appendix C)

## **Peer Review**

To be completed for Final Report.

## Findings

In this section we summarize information from the published and grey literature sources to address Guiding Questions 1-4. Much of the discussion with Key Informants was consistent with the salient topics that emerged from the body of literature, focusing primarily upon the need for, implications of, and barriers to the adoption of seamless, effective, and comprehensive transition care for children and youth with special health care needs (CSHCN).

We summarize the literature on the purpose and current approaches for transition care in the context of the six elements of transition care proposed by the *Got Transition*<sup>24</sup> framework (GQ1) followed by a discussion of resources, barriers and other contextual issues important to the implementation and adoption of transition strategies (GQ2). The results presented here are a combination of a summary of the literature and our Key Informant conversations, organized within the *Got Transition*<sup>24</sup> got transition framework. As noted previously, this framework is the most widely published and recommended by our Key Informants and serves as an organizing principle for the report. We present the state of the current research, identifying the sources and findings from evaluation studies of transition approaches in Guiding Questions 3. We present implications and areas for future research in Guiding Question 4.<sup>24</sup>

### Guiding Question 1. Description of interventions for transitions care

- m. What is the purpose of transition care and what are the theoretical advantages and disadvantages?
- n. What are the common components of transition care interventions or processes used in clinical practice for children/adolescents with special health care needs?
- o. How do currently used approaches to transitioning health care address the complexity of health issues including comorbidities and the presence of both physical and intellectual/developmental disabilities?

### Purpose of Transition Care (GQ1a)

Increased prevalence of chronic and disabling disease paired with improvements in early diagnosis and treatment of those conditions have led to increasing numbers of children and youth with special health needs (CSHCN) living into adulthood.<sup>15, 23, 26-29</sup> Overall, more than 90 percent of CSHCN now survive into adulthood, and an estimated 500,000 CSHCN make the transition to adulthood annually in the United States.<sup>4, 23, 30-37</sup> Unfortunately, health care delivery systems that support optimal transition from pediatric to adult providers have not kept pace with this growing population, and abrupt transfers from pediatric to adult health care fail to meet the needs of this population.<sup>38, 39</sup> Some studies have documented patients transferring to adult health care getting “lost in the system” or experiencing decreased access to care, both of which may be associated with poorer long-term health outcomes, impaired function, and high-cost emergency care.<sup>33, 40-42</sup>

The purpose of transition care is to optimize the quality of life and future potential of youth with special health care needs by ensuring continued access to and appropriate use of clinical care.<sup>1, 23, 43-49</sup> The American Academy of Pediatrics (AAP) suggests that good transition care follow the principles of the medical home in that it is coordinated, comprehensive, individualized, culturally competent, and patient-centered.<sup>15, 30, 40, 41, 44, 47, 50-56</sup> They also

recommend that the transition program promote skills in communication, decision-making, assertiveness, and self-care and enhance a sense of control and independence of health care for youth.<sup>44, 47, 55</sup> Several professional organizations including the American Association of Family Practitioners (AAFP), the American College of Physicians (ACP), the Society for Adolescent Health and Medicine, the Canadian Pediatric Society, and the National Association of Pediatric Nurse Practitioners and Nurses also endorse these functional goals.<sup>31, 35, 41, 57</sup>

Key Informants in this process stated strongly that all transition care should be based upon these principles, but that specific programs should be designed to match the specific needs of the patient population and the health care system. As such, there is no specific model program of care that experts in the field would endorse; rather they base their assessment of positive transition on clear implementation of the principles identified above, and described in the *Got Transition*<sup>24</sup> recommendations.

## Advantages

Proposed advantages of purposeful transition through organized programs are that they provide youth with access to subspecialists for ongoing care, promote competence in disease management, foster independence, social, and emotional development through teaching self-advocacy and communication skills, and allow for a sense of security for support of long-term health care planning and life goals.<sup>58, 59</sup> These concepts align well with those voiced by patients and their families.

Parents of CSHCN say that preventing deterioration and complications of existing health conditions during transition to adult health service is a top priority,<sup>60</sup> and post-transition perspectives of CSHCN are that they appreciate the increased autonomy received in adult clinics but felt a transition program (as opposed to a transfer of care) would be beneficial.<sup>61, 62</sup>

Furthermore, the self-care behaviors that CSHCN learn from a well-executed transition program during adolescence may be useful during other periods of care transition, such as changes in residence, insurance, and personal preference.<sup>63</sup> Another advantage of transitioning is that eventually, as patients age, they will need additional targeted care for issues related to adulthood and aging. Adult providers are better suited to address adult issues such as pregnancy and comorbidities associated with adult lifestyle and ongoing aging, so establishing care early enough for them to follow the patient through adulthood may be helpful.<sup>58, 59</sup>

## Disadvantages

There is general agreement in the literature and among key informants that the advantages of a well-planned, tailored transition approach are many and that a poorly planned, unsupported transition of care from the pediatric to adult setting for individuals with special health needs can result in poor health outcomes. Certain populations may be at increased risk for adverse or worsening outcomes following a transition in care. In addition to the logistic and economic barriers faced by all pediatric patients with special health care needs, those patients with a chronic but not disabling condition may be particularly prone to challenges associated with adherence and continuity of care.

An inherent disadvantage of transition care includes a change in the health care provider and a move away from a familiar pediatric setting. As illustrated in a study published in 2011 that assessed the transition experiences and medical outcomes of a cohort of individuals with HIV acquired in childhood, the transition to adult care was more difficult than expected, and youth reported feelings of abandonment and sadness with the loss of patient-provider relationship after

transfer to adult health care. Almost one half of the participants who transitioned to adult care (19/42) reported problems with medication adherence. This study also reported that CD4 counts trended downward from pre- to post-transition.<sup>64</sup> Other studies report young adults with sickle cell disease transferring from pediatric clinics experiencing increased episodes of pain and greater mortality,<sup>65-67</sup> premature deaths after transfer for young people with congenital heart disease,<sup>28</sup> and high rates of rejection and allograft loss among youth with transplants immediately following transfer.<sup>28, 46, 58, 68, 69</sup>

Risk for poorer outcomes may be more pronounced among subgroups of patients. For example, a retrospective review of administrative and survey data of young adults with diabetes found that individuals in the lowest income group were less likely to attend an eye care visit in the two years after transition to adult diabetes care than individuals from other income groups.<sup>70</sup> Patients transitioning to a new health care team who did not change physicians were less likely to be hospitalized after the transition than were patients who changed physicians, regardless of whether or not they also transitioned to a new health care team.<sup>70</sup>

None of these disadvantages is related to good transition planning; rather these are disadvantages of transitioning out of pediatric care, which is generally centered around a medical home, including care coordinating with specialists, into an adult system that may not be prepared to manage young adults with special health care needs, and that may offer fewer care coordination services across multiple subspecialties. Theoretically, disadvantages of transition care could include stigma for the individual, or delayed entry into adult care. At the system level, high costs of providing care and lack of reimbursement may be disadvantages. We did not identify any documented disadvantages of transition care in the literature.

## Components of Transition Care (GQ1b)

While extensive literature endorses the need for transition planning for CSHCN, a range of approaches to improving the process and structure of transition care has been proposed, and no gold standard for transition care exists.<sup>29, 30, 61, 69</sup> The most common practice models are: a primary care model where the general practitioner provides ongoing medical care and care coordination, a transition coordination model where a consultative, multidisciplinary team facilitates the transition, an adolescent-focused model where youth transition to adult care through an adolescent subspecialist service, and a disease-specific or subspecialty-based transition program, which may use one of the models described above in a disease-specific way.<sup>29, 37, 54, 71-73</sup>

Key informants noted that varying approaches to transition care may be warranted and appropriate given the heterogeneity of CSHCN, both by diagnosis and by level of medical complexity. For example, discussion of infection control policies will be an important aspect of transition programs for patients with cystic fibrosis,<sup>74</sup> while transition programs for youth with HIV will likely incorporate strategies to address the stigma surrounding this diagnosis.<sup>61</sup> The format that is adopted also depends on the facilities and resources available.<sup>27, 29, 31, 43, 47, 53, 56, 59, 75-77</sup> Finally, the Society for Adolescent Medicine recommends that one of the basic principles for successful transition is “to have individualized and flexible enough programs to meet the needs of young people and their families.”<sup>34</sup>

Despite documented variation and a focus on flexibility in transition approaches, there is a core set of common components of quality transition care. Experts, including this project’s Key Informants, point to the *Got Transition* Six Core Elements of Health Care Transition<sup>25</sup> as a

framework on which to build best practice transition programs. *Got Transition* is a collaborative network supported by The National Alliance to Advance Adolescent Health.

The core elements defined by *Got Transition*<sup>24</sup> mirror the algorithm for best practices in the clinical report titled “Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home” that was jointly published by the AAP, AAFP, and ACP.<sup>1</sup> These core elements, or components, of health care transition are transition policy, transitioning youth registry, transition preparation, transition planning, transition and transfer of care, and transition completion.<sup>24</sup>

Each of these components can be augmented by the use of specific tools to address issues including comorbidities, the presence of both physical and intellectual disabilities, and confounding psychosocial circumstances. Different tools may be used for different groups of patients or different clinical settings. Incorporation and implementation of different tools also may vary based on available resources and support services. Most published transition programs incorporate multiple components and tools, making assessment of individual components difficult.<sup>78</sup> We have organized the discussion and review of the literature addressing transition care components (GQ1b) around the *Got Transition*<sup>24</sup> recommendations for complete transition planning.

## Transition Policy

An explicit transition policy that describes the practice’s approach to health care transition outlines goals of the program and clarifies the roles and responsibilities of the youth, family, and health care team.<sup>47, 52, 75, 292</sup> Development of policies may involve both pediatric and adult transition teams.<sup>27, 71, 79</sup> Patients cared for by family practitioners may theoretically have the same primary care physician in both childhood and adulthood. However, these patients may still need to transfer some of their care from pediatric to adult specialists, and may still need a process to help them assume increasing responsibility for their own care as they age.

The transition policy typically includes a timeline with a suggested age for beginning the transition process and tentative deadline for ultimate transfer of care.<sup>44, 75</sup> It is frequently recommended in the published literature that transition care start early, perhaps as young as 11 to 12 years of age, to allow for an adequate period of preparation,<sup>27, 32, 35, 42, 47, 52, 53, 61, 75, 77, 80, 81</sup> and some advocate for beginning the process at time of diagnosis.<sup>82</sup> There is little empirical evidence, however, about optimal age at which to begin the process.

Timing of transfer takes into account the youth’s cognitive development, physical abilities, and environment, which includes socioeconomic characteristics and psychosocial resources including family or peer support.<sup>30, 51, 77, 82, 83</sup> In particular, it is typically recommended that transfer of care not take place during a period of health crisis, especially if the support system is unstable.<sup>77, 84</sup> Nonetheless, having a target age of transfer could be useful to catalyze transition activities to plan and prepare for the ultimate transfer of care. Age 18 years is most commonly considered an acceptable age for transfer.<sup>27, 71, 80, 82, 83, 85</sup> However, the range of suggested age of transfer is from 12 years<sup>78</sup> to 25 years.<sup>75</sup> The wide range of suggested transfer age in the literature may underscore that timing of transfer of care should be individualized.<sup>78</sup>

*Got Transition*<sup>24</sup> recommends that transition policy be visible and that supporting documents such as brochures, posters, and web-based information be created to help implement the policy.<sup>1, 75</sup> Other suggestions for introducing anticipated transition that we identified in our search were transition alert letters, videos, and pamphlets or books.<sup>26, 86</sup> Pamphlets, in particular, theoretically offer an accessible, portable, convenient, and cost-effective means for information distribution.<sup>86</sup>

## Transition Registry

Practices can maintain transition registries to help identify patients with special health care needs at the appropriate chronologic age for transition and enable a system for monitoring which steps of the transition process still need to be completed.<sup>1, 75</sup>

## Transition Preparation

Key Informants reported that providers often are not trained to manage the challenges associated with transition and are unprepared to care for CSHCN who transfer to adult care, and this opinion is echoed in the published literature. Transition care involves active preparation on the part of providers, transitioning youth, and their families. This process has been referred to as “capacity building,” where everyone involved works toward an enhanced capacity for empowerment, self-determination, and advocacy when needed.<sup>79</sup>

Educational needs for both the clinical team and the patients and their families in preparation for transition may also exist.<sup>23, 32, 44, 84</sup> First, some health care providers may need additional education on transition care topics and professional training in caring for adolescent patients.<sup>1, 32</sup> Team members may be supported with continuing medical education programs that are tailored for their specific functional needs as a member of the transition team.<sup>66</sup> Second, a formal transition curriculum can be a part of the transition, and can be developed to address medical and non-medical issues including disease-specific topics, skills training in communication, decisionmaking, creative problem solving, assertiveness, self-care, self-determination, and self-advocacy.<sup>30, 32, 38, 47, 52, 53</sup>

Youth and family report a need for education about the differences between pediatric and adult care and may receive ongoing anticipatory guidance regarding what to expect from adult specialty care,<sup>1, 32, 61</sup> as well as instruction for how to navigate the system of entitlements, such as Medicaid and Supplemental Security Income.<sup>55, 61</sup> Transition preparation is recommended to include support for youth and their family.<sup>30, 35, 47, 55, 59, 76, 84</sup> Both family and peer support groups or mentoring programs have been proposed as forms of support and education during the transition process.<sup>1, 54, 75, 77, 82, 87</sup>

*The Adolescent Leadership Council (TALC)*<sup>88</sup> is an example of a group-mentoring program that brings together high school students with chronic illness and college student mentors with chronic illness. Participants have reported that they learned to better care for their illness and gained skills talking about their illness, and investigators reported a small increase in transition readiness scores for participants in the program, although successful transitioning has not been evaluated.<sup>88</sup>

Another example is the *Good2Go Transition Program*,<sup>89</sup> which used psycho-educational transition groups to discuss issues of self-advocacy, independent behaviors, health lifestyle issues, and health care access strategies. These groups were also available to support parents in growing independence of their adolescent.<sup>41</sup> Mentoring via email or internet chat rooms has also been proposed but not evaluated.<sup>54, 90</sup> Summer camps are another option that could provide opportunities to increase social networks and promote development of self-management skills.<sup>91</sup>

Transition programs typically attempt to be family-centered and to engage the family in the process by recognizing that the family’s role in care of the young adult is not necessarily diminishing.<sup>47, 54, 61, 77, 81, 92</sup> Opportunities for family engagement may include concurrent visits, specific foci on fathers, and modeling of healthy lifestyles<sup>46, 48, 93</sup>

## **Transition Planning**

### **Individualized Transition Plan**

The literature outlines specific goals and actions for a formal, individualized transition plan which should be documented in the medical record.<sup>1, 4, 46, 47, 52, 75, 92, 77, 82, 94</sup> The transition plan generally includes goals for achieving self-care, health care decision-making, and self-advocacy as well.<sup>33, 35</sup> Careful documentation in the patient chart of intent to transfer to an adult health care provider and details regarding transition conversations among patients and providers may predict successful transfer of care.<sup>63, 81</sup> The transition plan also documents the expectations for the adolescent's knowledge and understanding about his or her condition<sup>32</sup> and addresses strategies for securing health insurance.<sup>23</sup> Key informants provided information on the degree to which developing such a plan is time intensive, but essential for ensuring that the process goes well.

In theory, collaborative development of a transition plan helps parents learn to consider their child's future capacity in multiple domains such as education, employment and independent living, and it helps adolescents learn that they will be expected to take gradual increased responsibility for their health care.<sup>63, 95</sup> Multiple approaches may be used to facilitate communication; for example holding visits in a consultation room without examination equipment and the provider-patient dialogue taking place sitting around a table rather than behind a desk.<sup>96</sup>

### **Assessing Readiness**

The literature asserts that assessment of transition readiness can guide individualized interventions that promote appropriate patient education and skill development.<sup>1, 32, 40, 75, 76, 86</sup> Readiness assessment tools also offer the added advantage of measuring overlapping constructs or assessing the continuum of transition preparedness as opposed to the simple "yes/no" questions on checklists.<sup>33, 40, 76</sup>

### **Legal Considerations**

Some youth with special health care needs will not attain independence due to significant developmental or functional disabilities, and discussions about guardianship, health care power of attorney, and other legal issues need to take place during transition preparation.<sup>1, 97</sup> Medical providers providing transition care must recognize that parents appointed as legal guardians will remain heavily involved in the youth's care for the remainder of the individual's life.<sup>30</sup> The transition period also provides an opportunity to hold end-of-life and emergency planning discussions collaboratively and without urgency.<sup>53, 97</sup>

### **Transition and Transfer of Care**

Given the diversity and complexity of young adults with special health care needs, a multidisciplinary approach to transition seems most likely to ensure a transition process that meets the range of medical, cognitive, and social needs.<sup>26, 30, 66, 98</sup> Health care staff members involved in transition may include physicians, nurses, case managers, social workers, and peer mentors.<sup>66, 98</sup> Nonetheless, the Society of Adolescent Medicine emphasizes the need for one designated professional to take responsibility for the process together with the patient and the family.<sup>34</sup> One of the more common suggestions is for that individual to be an assigned transition coordinator and advocate (see description in section on resources).<sup>38, 41-43, 46, 47, 59, 63, 77, 81, 99</sup>

Checklists, portable medical summaries (e.g., health care passport), and meeting the adult provider prior to transfer are recommended (Table 2) as part of the transfer of care process.<sup>27, 441, 28, 51, 74, 76, 77, 83, 93, 98</sup>

**Table 2. Tools to aid transition and transfer**

Tool	Description	Examples
Checklists	<ul style="list-style-type: none"> <li>• May be placed in the patients' charts</li> <li>• Allows providers to keep track of the skills and knowledge that the transitioning youth needs to acquire before transfer of care</li> <li>• May be used to ensure that all crucial education topics are covered</li> <li>• May divide tasks based on chronological age</li> </ul>	<ul style="list-style-type: none"> <li>• Spina Bifida Transition Program at the University of Wisconsin<sup>59</sup></li> <li>• Clinical Pathway Document developed by the ON TRAC program at British Columbia Children's Hospital<sup>100</sup></li> <li>• Checklist developed at the Center for Inflammatory Bowel Disease at Children's Hospital Boston<sup>101</sup></li> </ul>
Portable Medical Summary	<ul style="list-style-type: none"> <li>• May include past medical and surgical history, list of current medications, allergies, immunizations, pertinent family and social history, most recent diagnostic and imaging studies, disease specific parameters (i.e., cardiac anatomy and physiology for patients with congenital heart disease), upcoming appointments, and contact information for health care providers</li> <li>• Updated at each visit and a copy should be included in the medical record and given to the adolescent to keep</li> <li>• May require special adaptation for those with intellectual disability to include non-written forms of communication such as pictures or tape recordings</li> </ul>	<ul style="list-style-type: none"> <li>• <i>MyHealth Passport</i> developed by the Good2Go Transition Program at the Hospital for Sick Children<sup>89</sup></li> <li>• <i>Your Plan It</i> developed by the ON TRAC program at the British Columbia Children's Hospital<sup>100</sup></li> </ul>
Meeting the Adult Provider	<ul style="list-style-type: none"> <li>• May alleviate the lack of trust, fear, and anxiety that the youth and family may have related to acquiring a new adult provider</li> <li>• May increase confidence and comfort among transitioning youth</li> <li>• May promote higher rates of retention in adult clinics after transfer</li> <li>• Joint clinics are a strategy for patients to meet the adult provider(s) prior to the transfer of care</li> <li>• Joint clinics specifically help facilitate communication and convey trust among pediatric and adult members of the transition team</li> </ul>	<ul style="list-style-type: none"> <li>• Spina Bifida Transition Program at the University of Wisconsin<sup>59</sup></li> <li>• Cystic Fibrosis Transition Program at the University of Michigan<sup>102</sup></li> <li>• Young Persons Clinic at the Royal Manchester Children's Hospital<sup>103</sup></li> <li>• University Diabetes Center in Italy<sup>104</sup></li> <li>• Transition Pilot Program at St. Jude Children's Hospital<sup>102</sup></li> </ul>

## Transition Completion

Written communication and good documentation may serve to promote continuity of care.<sup>1, 32, 34, 51, 61, 75, 79, 90, 99</sup> Maintaining an up to date medical summary that is portable and accessible enables such communication.<sup>4, 46, 80</sup> The medical summary for transition includes recommendations for treatments that work best physiologically and psychologically for the individual patient and family, as well as details such as advanced directives.<sup>53, 86</sup> Providing the patient with a copy of the portable medical summary may help with communication and allows

the patient an opportunity to include any personal information and advanced directives that he chooses.<sup>28, 41, 75</sup> It may be helpful to have youth prepare their own referral letter to clarify their medical needs and set objectives for self-management, promoting identity development and responsibility.<sup>85</sup>

It is typically recommended that the referring pediatric team be available to the adult team as a resource immediately after the transfer period.<sup>75</sup> A transition coordinator can also help ensure transfer is completed by bridging communication between the pediatric and adult teams.<sup>32, 75</sup> Some programs have included a celebration, including certificates, letters of gratitude to the health team, and graduation ceremonies.<sup>39, 80, 94, 105</sup> These strategies may address the feelings of abandonment and sadness with the loss of patient-provider relationship that youth have reported after transfer to adult health care.<sup>70</sup>

After complete transfer of care has taken place, the transition process should be evaluated to highlight areas for future improvement.<sup>54, 75, 79, 82, 84</sup>

## **Transition in the Face of Patient Complexity (GQ1c)**

Youth with special health care needs often have a complex array of medical and sometimes psychological or psychiatric conditions, reinforcing the need for individualized transition care. Each of the general components above can be personalized or augmented by the use of specific tools to address the complexity of health issues including comorbidities, the presence of both physical and intellectual disabilities, and confounding psychosocial circumstances.

The following may be helpful for addressing complexity in patient populations: maintaining a flexible policy regarding the timing of the transfer, adequate preparation through focused education and support, development of individualized transition plans, utilization of a transition coordinator, and facilitated communication between multidisciplinary providers and patient or family through use of a portable medical summary.

Our Key Informants noted that while all adolescents with a chronic condition would need some sort of transition support, their diversity in terms of conditions and complexity affects what is needed where. For the highly complex cases, the range and quantity of resources may be available, for example, only at centralized programs, usually at academic centers. For some types of chronic conditions, on the other hand, and in the absence of multiple conditions, community based programs can and should be developed. These would include, for example, transition care for children with diabetes, as contrasted with a transition program for youth with cerebral palsy, a condition complicated by intellectual disability and feeding problems.

## **Guiding Question 2. Description of the context for implementing transition care**

- p. How widely available are programs or approaches to transition care within the health care setting for children/adolescents with special health care needs?
- q. What are the resources needed to implement transition care?
- r. What are the specific barriers to implementing transition care or processes for children/adolescents with special health care needs?
- s. Who delivers transition interventions and what training is required to implement identified approaches to transition care for children/adolescents with special health care needs?

## **Availability of Transition Programs (GQ2a)**

The data on availability of transition programs are limited, but the little research that has been done suggests that these programs are not widely available. About one-half of diabetes centers in the United States reported having a structured transition program,<sup>106</sup> and only 18 percent of pediatric rheumatology units in the United Kingdom had a dedicated adolescent clinic.<sup>44</sup> Transition services might be especially inaccessible if one is receiving public services in childhood; a survey of state mental health administrators from across the United States found that only 5 percent reported the existence of any type of programs or services within the State mental health system to transition mental health treatment from the child to adult service system.<sup>107</sup> Thus, the findings from limited research converge around a general inaccessibility of transition programs and services, with anywhere from 5 to 50 percent of agencies or clinics offering such programs. Key Informants affirmed that the landscape of transition care approaches seen in practice is shaped by availability and resources rather than by standards defined as best practice, and that resources vary substantially.

Dedicated transition programs are not only relatively inaccessible, but many pediatric clinics do not have formal plans for transitioning their pediatric patients with special health care needs to adult care. In a survey of providers of pediatric HIV care in the United States, 81 percent had designated a transition coordinator, but few clinics had established policies to define the details of transition.<sup>108</sup> Established transition policies were also relatively uncommon in a survey of primary care pediatricians in the United States; only 13 percent had written policies about the transition from pediatric to adult care.<sup>109</sup>

Aside from information on the availability of specific transition programs or plans, the proportion of youth with special health care needs who are given information and assistance with transition (either within the context of a transition program or through their pediatric provider) is low. Nationally, only about 40 percent of youth with special health care needs meet criteria for adequate transition support, with the other 60 percent being unprepared for transition in at least one area.<sup>108, 110</sup> Similarly, among young adults with diabetes only 50 percent reported receiving specific adult provider or clinic recommendations. Fewer than 15 percent of participants reported receiving written transition materials, having a specific visit to discuss transition, or meeting the adult provider before transition.<sup>111</sup> Finally, less than 40 percent of a sample of young adults with sickle cell disease received any preparation before transferring from pediatric to adult care.<sup>112</sup>

In sum, the limited data on the availability of transition programs and information suggests that that majority of transitioning youth with special health care needs do not have access to a specific program to aid with their transition, nor to the necessary information or planning to make the transition a smooth process.

Our search for transition programs with information available online identified specific programs, presented in Appendix C. Few of these programs are evaluated in the published or grey literature. The grey literature search also retrieved a variety of online resources for transition care for individuals with special health needs.

## **Resources to Implement Transition Care (GQ2b)**

The resources needed to implement transition care vary, of course, by the type or complexity of the program or service. Commonly described resources include space, time, personnel, materials, and systems for knowledge transfer. Key Informants noted that successful implementation of a transition care program requires significant staffing and resources.

## Space

Like all other health care programs, transition programs require dedicated space. In some transition programs, space is used to create a dedicated transition clinic.<sup>38, 103, 113-116</sup> In other transition programs, space is needed to house a dedicated transition coordinator or other personnel within a pediatric clinic. Still other transition programs require space to convene transition-related activities such as peer support or mentoring groups.<sup>88, 117</sup>

## Time

Time is necessary to develop and implement transition policies, establish and maintain transition registries, prepare patients and families for transition, and transition planning and actual case transfer. For example, transition preparation, planning and case transfer all require communication and coordination between pediatric and adult providers.<sup>27, 29, 59, 95, 118-120</sup> This requires patients and their families, pediatric providers, and adult providers to dedicate time to these activities.

It may be particularly important for adult providers to allow additional time for the first post-transition because this may help build rapport with transitioning youth and their family and help the provider understand the youth's health care needs.<sup>59</sup> Flexibility in terms of when the first adult appointment is scheduled may also be helpful. For example, scheduling the first adult provider appointment close in time to the last pediatric appointment, instead of following the regular visit schedule (which means that the patient might not meet with the adult provider for 6 months or more after transition), may ease the transition process and improve adherence.<sup>120</sup>

## Personnel

Personnel are also required at each stage of the transition process from policy development to transition completion but are not used in the same way across transition programs. Some transition programs are separate, stand-alone clinics.<sup>56, 113-115</sup> These programs require front-end, clinical, and back-end staff to support transition-related activities. Other transition programs exist within pediatric clinics and require personnel with transition-specific responsibilities such as a transition coordinator.<sup>102, 113, 121-124</sup> These programs must either hire staff whose responsibility is to manage transition processes or designate a portion of an existing staff member's responsibilities to transition-related tasks. Finally, other programs convene transition-related activities such as peer support or mentoring groups.<sup>88, 117</sup> These programs also must hire staff to coordinate and provide services.

A dedicated transition coordinator is a common approach to implementing a transition program.<sup>32, 59, 76, 86, 102, 113, 118, 120-125</sup> The transition coordinator works with the transitioning youth to set developmentally appropriate goals, manage the transfer of information from the pediatric to adult provider, assist in making appointments with adult providers, arrange transportation, and facilitate the transfer from the family-centered orientation of pediatric care to the more individually oriented adult care system. The transition coordinator may attend the first adult appointment,<sup>86, 118, 120</sup> and sometimes follows-up with the patient multiple times after transition to ensure that they are satisfied and are getting the care they need.<sup>120</sup> An advantage to assigning a care coordinator is that this staff member can assume a role that spans both pediatric and adult services as well as leverage already available community resources to meet individualized needs of transitioning youth.<sup>36, 76, 86</sup>

Several transition programs have reported using an advanced practice nurse as the transition coordinator,<sup>36, 84, 96, 98, 113</sup> with the theoretical advantages being their capacity to attain dedicated

time for transition initiatives and their ability to serve as an expert, educator, researcher, leader, and consultant.<sup>32, 48, 63, 77, 126</sup> Alternatively, a community-based “navigator”, or facilitator, offers the advantage of being unencumbered by an affiliation with any particular service system.<sup>79</sup> Regardless of whether transition coordinators are used, both pediatric and adult providers and their staff need training in issues of adolescence.<sup>1, 68, 127, 128</sup> Adolescence brings with it specific challenges for the treating clinician – particularly when the adolescent has special health care needs – such as determining the degree of autonomy versus family involvement appropriate to that individual, addressing risky behavior, and providing information in a way that is appropriate to their level of cognitive development (e.g., difficulties in considering long-term consequences of behaviors or nonadherence). As is discussed in more detail in GQ2c, many providers (both adult and pediatric) do not receive specific training in providing care to adolescents, and may be inadequately prepared to deal with adolescent issues such as puberty or lack of adherence to medication and treatment regimens due to the desire to be viewed the same as one’s peers. For a transition program to be most effective, training in providing care can be helpful for the transition coordinator as well as for pediatric and adult primary care providers.

Further, pediatric providers need training in transition processes and adult providers need training in treatment of complex medical conditions beginning in childhood (e.g., cerebral palsy, Down syndrome, autism spectrum disorder); this is particularly true for adult physicians who treat patients with cognitive impairments.<sup>1, 95</sup>

Perhaps the most important resource needed to implement high-quality transition care is a productive collaboration between pediatric and adult providers.<sup>27, 29, 59, 76, 86, 95, 118-120</sup> This collaboration can take a number of different forms, such as scheduling one or a series of overlapping appointments with a pediatric and adult provider,<sup>29, 86</sup> a joint clinic that includes both pediatric and adult providers<sup>26, 76, 119</sup> or commencing appointments with an adult provider prior to transition.<sup>118</sup> Other effective strategies are having the pediatric provider attend the first appointment with the adult provider,<sup>119</sup> and having the pediatric team followup with the transitioning youth at set intervals after he or she has transitioned into adult care.<sup>118</sup>

Finally, trained personnel who are knowledgeable about the health insurance options available to transitioning youth with special health care needs are important to ensure that youth remain covered during the transition.<sup>129</sup> Adolescents and young adults with a chronic disease are less likely to have health insurance than any other age group,<sup>118</sup> and a trained staff person who can help them navigate changes in insurance coverage during the transition to adulthood can be valuable to avoid gaps in coverage or care. While the allowance for children to remain on parental insurance until age 26 and other expansions associated with the Affordable Care Act have the potential to mitigate some of these issues, it will still be important to provide support for navigating this changing benefits and access landscape.

## Materials

Written guidelines<sup>1, 27, 68, 98, 118, 130, 131</sup> can include information such as the age at which transition should be initiated, the age by which certain behaviors are expected to have occurred, how youth readiness will be determined, as well as the specific staff responsibilities for different aspects of the transition process.<sup>1, 98</sup>

Although written guidelines can serve as a type of transfer checklist, formal transfer checklists designed to guide pediatric provider actions and transfer knowledge to adult providers are also available.<sup>27, 41, 59, 120</sup> A transfer checklist might, for example, be kept on file with the pediatric provider, be sent to the adult provider, and include information not necessarily

contained in the medical record such as transition readiness, noncompliance issues, or possible problems with insurance after transition.<sup>120</sup> Information transfer ideally occurs well before the transition, so adult providers can understand the complications and challenges they might encounter.<sup>27</sup> Information transfer well in advance may be particularly important if the patient's condition is severe and requires emergency care after transitioning from pediatric care but prior to the first adult ambulatory visit.

A number of specific tools have been proposed to assess patient readiness and may be incorporated into guidelines and checklists. These need to be acquired or developed at the clinic level. Examples include the "Readiness to Transition Questionnaire"<sup>130</sup> and a self-management scale to help providers determine how much of the youth's own care he or she has taken responsibility for (e.g., taking medications independently).<sup>27</sup> Another tool is *The Transition Readiness Assessment Questionnaire* (TRAQ), which incorporates the Transtheoretical Model for the five stages of change into a 5-point ordinal scale for measurement of completed transition tasks specifically for youth with special health care needs.<sup>33</sup> Disease specific transition readiness tools have also been developed for cystic fibrosis, cerebral palsy, and diabetes.<sup>29, 76, 132</sup> The *Self-Management Scale*, piloted to assess transition readiness in youth with cystic fibrosis, was found to be a better predictor than age for success in transfer to adult care.<sup>27, 29</sup>

Additionally, for youth with special health care needs who also have cognitive impairments, an assessment of cognitive, developmental, and adaptive functioning will be critical in determining transition readiness, the optimal level of involvement by parents, and to further inform adult providers.<sup>30</sup>

In addition to written guidelines, transfer checklists, and readiness assessments, patient-and family-centered educational resources encouraging autonomy, self-advocacy, self-care responsibility, and treatment adherence may also be important.<sup>41, 66, 68, 98</sup> Education materials that are electronic, such as internet sites or mobile phone applications, are accessed more easily by young people.<sup>71, 93</sup> Teens have also identified games, animation, messaging, and chat features as desirable features for such education materials.<sup>93</sup> Workbooks used as learning tools also can help providers assess the patients' knowledge and understanding of their disease process and transition needs.<sup>61</sup> Gilliam and colleagues<sup>98</sup> describe the development of a workbook for transitioning youth with HIV/AIDS that uses a developmental approach to teach and reinforce life skills and health information. Although the specific approach to patient education can be tailored based on the resources of the clinic and the needs of the population, it is an important part of improving adherence and preparing the youth to be responsible for his or her own care.

## **Tools for Transferring Knowledge Between Providers**

Key Informants recommended that care plans be in place at the time of patient transfer. Similarly, the literature asserts that a system to transfer knowledge and information from the pediatric provider to the adult provider is important.<sup>26, 27, 41, 59, 86, 120</sup> One example is the use of a transfer summary or checklist, kept on file with the pediatric provider and sent to the adult provider, which includes important information not necessarily contained in the medical record such as a comprehensive summary of history of care, transition readiness, noncompliance issues, possible problems with insurance after transition, and recommendations for what might work best for the youth psychologically or physically.<sup>26, 86, 120</sup>

Towns and colleagues<sup>27</sup> noted that the transfer of information would ideally happen well before the transition actually occurs, so that the adult care team can have a full understanding of the extent of complications and challenges they might encounter. Having this transfer occur

ahead of the first adult appointment could also be important if the youth with special health care needs requires emergency care after transitioning from pediatric care, but prior to their first ambulatory visit with the adult provider. This recommendation was endorsed uniformly by Key Informants.

## **Barriers to Implementation of Transition Care (GQ2c)**

The barriers most commonly described in the literature are cost and insurance problems, issues of adolescent development, resistance to changing providers, differences in the culture of pediatric and adult care, problems with adherence, and lack of provider training.

### **Cost and Insurance Problems**

Changes in insurance and gaps in coverage are common in transition care, per the literature and the Key Informant interviews.<sup>30-32, 58, 66, 75, 86, 98, 110, 118, 128, 133-135</sup> Key Informants noted that the challenges to implementing seamless transition of care is complicated by significant differences between pediatric and adult health care practice, stemming from issues related to coverage, eligibility, and other financial disincentives. When children and adolescents age out of Medicaid eligibility or their parents' insurance, options for obtaining coverage may be limited or nonexistent,<sup>134</sup> and adolescents and young adults with special health care needs are less likely to have health insurance than any other age group.<sup>118</sup> Up to one-third of youth experience gaps greater than 6 months in health care coverage when moving from a pediatric to adult provider,<sup>136</sup> and between 15 and 30 percent of young adults with special health care needs have no insurance coverage.<sup>108, 134</sup> Lack of insurance coverage during and after transition, as well as greater difficulties getting needed services for those receiving publically funded health care in adulthood<sup>133</sup> represents a significant barrier to implementing transition services, with serious implications for care throughout adulthood. Further, many young adults with special health care needs have difficulty maintaining employment, which can pose additional challenges to paying for health care, even if they have insurance coverage.<sup>86</sup>

Medical providers are often held to benchmarked standards for volume of patients seen and levels of reimbursement within their practice. Transition care requires a significant amount of provider time, which results in a decrease in the number of patients seen by an individual provider. However, this care does not result in a substantial increase in per visit reimbursement and can therefore translate into a financial loss to clinics that provide this type of service. The age of transition often corresponds to a time when insurance coverage and benefits change. These insurance changes can result in decreased access to care for young adults and lack of coverage for those clinics that provide transition care further impacting reimbursement for services. In addition, transition care incorporates multidisciplinary services, which can be costly to those clinics that do not utilize these services for other patients. With the recent focus on pediatric medical homes, many pediatric clinics have greater access to multidisciplinary care, so this cost difference might be more significant for the adult clinics typically designed for individual focused care.

### **Issues of Adolescent Development**

A number of developmental issues arise during adolescence that can be barriers to successful transition care.<sup>29, 58, 66, 75, 78, 80, 110, 118, 128, 135</sup> Risky behavior, substance abuse, and concerns about sexual health all peak at this time. Furthermore, adolescence is a time when peers take on greater importance, and youth with special health care needs can make great effort to appear "normal" to

their peers. Many adolescents have limited experience with financial independence or making their own decisions, and may have difficulty keeping appointments and being responsible for their own medical care. They may not have developed the skills to independently negotiate the adult service system, which is more complicated and fragmented than the pediatric system.<sup>110</sup> Many have not reached a level of maturity to be able to fully appreciate the long-term implications of their decisions.<sup>29</sup>

All of these behaviors, which are common to adolescence, have a direct negative effect on the transitioning youth's ability to adhere to complicated medical regimens, and so are particularly troublesome for children with special health care needs.<sup>108</sup> Further, because most providers are trained to provide care to children or adults, and adolescents are neither of these, few providers have training in how to treat adolescents, and it can be very difficult to know the most effective way to deliver care to this population.<sup>98, 110, 135</sup>

Finally, some youth with special health care needs have conditions that worsen in adolescence, such as increased difficulties with glycemic control for youth with diabetes<sup>80</sup> or the emergence of comorbid mental health problems, which are common among many youth with special health care needs.<sup>80, 135</sup>

## **Resistance to Changing Providers**

Youth and parents often resist changing providers.<sup>30, 32, 37, 58, 59, 66, 75, 78, 86, 118-120, 128, 137</sup> It can be very difficult for families of youth with special health care needs to leave their familiar pediatric clinics for caregivers who are unfamiliar with their history,<sup>32, 37, 66</sup> and to “start over” and develop relationship with new providers.<sup>30</sup> Many youth express a preference for their pediatric providers, and consider the adult service system to be impersonal.<sup>78, 86</sup> Further, youth and their families express concern that the quality of care will not be as good in the adult setting as that they are receiving in the pediatric setting.<sup>86, 119</sup> Reluctance about transitioning care to an adult provider can be compounded for youth who have medical conditions that carry with them stigma, such as HIV/AIDS.<sup>98, 118, 128</sup>

Resistance to changing health care providers can also occur on the part of the pediatric provider.<sup>32, 37</sup> Pediatricians may be reluctant to transfer care to another physician who does not have a longstanding relationship with the youth with special health care needs, either because pediatricians feel that they can provide the best care for the youth and family, or because they are unaware of community and adult resources.

## **Differences in the Culture of Pediatric Versus Adult Providers**

Inherent differences in how pediatric and adult clinics are structured, as well as in expectations for transitioning youth can pose another barrier to effective transition care.<sup>37, 58, 75, 98, 118, 119, 135</sup> Pediatric providers may be more proactive in ensuring patients have followup appointments and prescription refills, whereas adult providers place more of the burden of responsibility on the individual. Further, pediatric clinics are more family-centered, focused on developing a treatment plan that works for the CHSN and his or her family. Adult clinics, on the other hand, function by treating the patient as an autonomous adult who is expected to make his or her own informed decisions.<sup>37, 135</sup> Although this emphasis on personal agency and self-sufficiency for adult patients compared with pediatric patients is developmentally appropriate, it can be difficult and overwhelming for the transitioning youth.

The adult health care system currently tends to provide more fragmented care than the pediatric health care system, although an increasing emphasis on accountable care may lead to

changes.<sup>119</sup> Not only is case management minimal in adult medical practices,<sup>98</sup> but medical and psychosocial services are particularly fragmented, even though transitioning youth with special health care needs often have comorbid psychiatric disorders that need to be addressed in addition to their complex medical needs.<sup>118</sup> The need to make multiple appointments with different providers to get medical and psychosocial needs met through the adult care system, compared to the one-stop shop of pediatric providers, can pose a barrier to successful transition care.

## **Problems with Adherence**

Although likely confounded with issues of adolescent development (e.g., difficulty considering long-term implications of decisions and behaviors) or differences in the structure of pediatric versus adult clinics (e.g., more hands-on followup to ensure adherence in pediatric clinics), problems with adherence are common in transition-aged youth with special health care needs.<sup>58, 66, 75, 98, 118, 128, 135</sup> Problems can include forgetting to take medications, running out of medications, and not showing up for scheduled appointments. Some youth with special health care needs may feel “burnt out” on managing their conditions, and might not seek maintenance care.<sup>86</sup>

Non-adherence is one of the leading causes of organ rejection, and older adolescents and young adults have the highest rates of non-adherence.<sup>51, 120, 138</sup> Young adult patients with diabetes have high rates of non-attendance after transfer to adult care and less frequent clinic contact is associated with poorer glucose control.<sup>28, 56, 90</sup> Youth with diabetes have higher rates of hospitalization because of acute hyperglycemia within two years after transfer.<sup>70</sup>

## **Lack of Provider Training in Child-Onset Conditions**

Most adult providers lack training in childhood-onset conditions. Key Informants noted that internal medicine providers often are not trained to manage the challenges associated with transition and are unprepared to care for CSHCN who transfer to adult care. In part, they may reflect a lack of familiarity at all with specific chronic or disabling health care conditions that originate in childhood.

Data from the literature support the Key Informant input; transitioning youth often report that adult providers do not have the skills or knowledge about childhood conditions to most effectively treat them,<sup>78</sup> and indeed this appears to be the case.<sup>18, 66, 133, 137</sup> This lack of knowledge can lead to reluctance by adult providers to accept responsibility for adolescents who have complex physical and psychological needs,<sup>37, 98</sup> leading to difficulty finding adult providers,<sup>1, 29, 31, 119</sup> especially for youth with significant cognitive limitations.<sup>30, 119</sup> In one example study, more than half of pediatric neurologists were unable to find adult neurologists willing to care for patients with severe disabilities.<sup>119</sup>

## **Other Barriers**

A number of other barriers to implementing transition care are mentioned sporadically in the extant literature. Properly assessing and understanding the implications of cognitive delays among youth with special health care needs can pose barriers to implementing successful transition care.<sup>29, 30, 58, 127</sup> For these youth, providers must determine the extent to which parents should be involved in decisionmaking, and difficult behaviors (which are common among many youth with significant cognitive impairments) may not be tolerated in adult provider offices.<sup>119</sup>

Similar issues arise for youth with physical disabilities, as parents may remain a critical part of decisionmaking if they provide substantial physical support.<sup>139</sup> Further, when youth with

special health care needs attend a college program, the physical distance between them and their primary care providers can be a barrier to successful transition care.<sup>133</sup> Finally, the lack of well-defined criteria for determining transition readiness makes decisions about when transition should begin difficult, especially if transition is initiated too early or too late.<sup>135</sup>

## **Delivery of Transition Interventions and Training (GQ2d)**

### **Who Delivers Transition Interventions?**

The National Heart Lung and Blood Institute (NHLBI) recommends that transition teams include physicians, mid-level practitioners (e.g., nurses or physicians assistants), and social service workers from both pediatric and adult care settings.<sup>66</sup> There are a number of transition programs that take this multidisciplinary approach and have multiple team members who can address the array of complex needs experienced by youth with special health care needs.

A clinic for youth with chronic rheumatic disease, for example, includes a nurse specialist, physiotherapist, occupational therapist, social worker, and the availability of vocational and sexual health counseling in addition to the primary care providers.<sup>29</sup> A transition clinic for renal transplant patients includes a pediatric nephrologist, renal nurse, youth health specialist, renal pharmacist, renal dietician, and social worker.<sup>68</sup> Finally, one transition team for youth with HIV includes a case manager, social worker, health care provider, and youth advocate or peer partner.<sup>98</sup>

In these programs, the focus is on assembling the personnel to address the medical and psychological needs of youth with special health care needs as they transition.<sup>66</sup> Depending on the specific needs of the youth, some of these professionals will play a more integral role in transition care, whereas others can be available for consultation as needed.<sup>140</sup> In some programs, an individualized team is assembled after assessing the needs of the transitioning youth.<sup>96</sup>

More common are transition programs whose personnel include one pediatric provider, one adult provider, and a mid-level provider who facilitates the transition between the pediatric and adult provider.<sup>37, 41, 59, 69, 86, 98, 119</sup> In these cases, the mid-level provider, often a nurse clinician, takes the role of the “transition specialist” by coordinating care from the pediatric to the adult provider, and ensuring that the appropriate information is transferred. In one model, the nurse practitioner manages the care of the transitioning youth during his or her last years with the pediatric provider, and then becomes the primary provider once the youth has transitioned to the adult care system.<sup>98</sup>

Although it is theoretically likely that the multidisciplinary team-based approach advocated by the NHLBI may result in better transition outcomes than programs that include health care providers only, these types of programs have not been tested against each other, and thus evidence for superiority is lacking.

### **What Additional Training is Necessary?**

Ideally both pediatric and adult providers should receive training in issues of adolescence,<sup>1, 68, 76, 127, 128</sup> and at the least, the mid-level provider serving as the transition specialist should receive this training.<sup>76</sup> Further, for adult providers and for the transition specialist, additional training in complex conditions that begin in childhood (e.g., cerebral palsy, Down syndrome, autism spectrum disorder, congenital heart disease) is necessary to provide effective treatments

in an adult setting for these populations;<sup>18, 96</sup> this is particularly true for adult physicians who treat patients with cognitive impairments.<sup>1, 95</sup>

An example of modules for training adult providers is presented in Osterkamp and colleagues<sup>127</sup> and includes topics such as the Health Insurance Portability and Accountability Act; family-centered care; and development of the healthy versus the chronically ill adolescent. Callahan and colleagues<sup>37</sup> suggested that physicians trained in a Medicine-Pediatrics residency program might be particularly well-suited to receive this type of training and to provide adult care to young adults with special health care needs.

Finally, because the transition specialist will need to work effectively with multiple providers and systems of care, training in how best to promote collaboration among providers and team members would allow the specialists to be maximally effective.<sup>125</sup>

### Guiding Question 3. Description of the existing evidence (Evidence Map)

- t. What patient groups/clinical conditions are represented in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- u. What is the length of followup in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- v. What outcomes are measured in studies on the use and evaluation of transition care for children/adolescents with special health care needs?

### Patients and Conditions Represented in Evaluation Studies (GQ3a)

We identified 21 studies reported in 23 publications<sup>13, 56, 68, 88, 102-104, 113-115, 117, 121-124, 141-148</sup> that evaluated a system of purposeful transition care. For this guiding question, we excluded studies that attempted to study the effects of moving generally into adult care without specific support and that did not evaluate a particular approach or system. See Figure 1 for detailed reasons for exclusion.

Among the 21 studies, eight<sup>56, 104, 113-115, 117, 122, 145, 148</sup> studied transition for adolescents with diabetes. Five studies<sup>13, 68, 121, 123, 141</sup> studied transition care in adolescents who had undergone organ transplant; all but one of these focused on kidney transplant. Two studied transition care in adolescents with cystic fibrosis.<sup>102</sup> The remainder studied a variety of conditions including congenital adrenal hyperplasia,<sup>103</sup> HIV,<sup>142</sup> epilepsy,<sup>143</sup> juvenile idiopathic arthritis,<sup>124, 144</sup> sickle cell disease,<sup>147</sup> and general illness<sup>88</sup> or disability.<sup>146</sup>

Ten studies were conducted in Europe: seven in the United Kingdom,<sup>56, 103, 113, 115, 141, 146, 147</sup> one in Germany,<sup>13</sup> one in Spain,<sup>148</sup> and two in Italy.<sup>104, 122</sup> Five studies were conducted in the United States,<sup>88, 102, 114, 123, 147</sup> three studies were conducted in Canada,<sup>68, 117, 143</sup> and one study was conducted in Australia.<sup>121</sup> One study included data from the United Kingdom and Australia.<sup>142</sup>

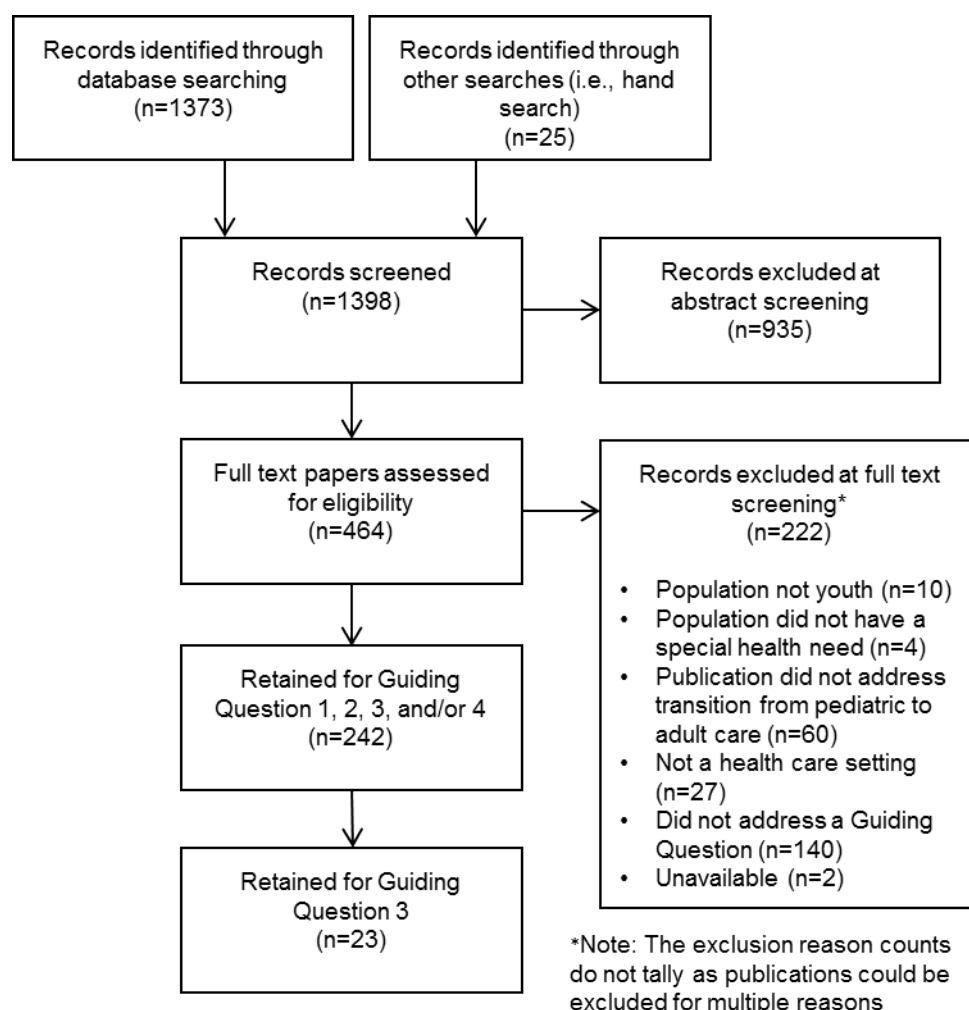
Very few studies used a concurrent comparison group, although some compared survey responses of individuals who had participated in transition care with those of individuals who had not, with transition generally not occurring concurrently. This is because most interventions are implemented at the system level and provided to all relevant patients at the same time; thus, these studies relied on data from individuals who had previously transitioned before the services were available as comparators. Outcomes were generally patient-reported, and focused mostly on issues such as satisfaction with the process or health-related quality of life. Some clinical outcomes are available in the literature; these include glycosylated hemoglobin (HbA1c) levels for patients with diabetes, and rates of organ rejection among transplant patients. Generally,

however, successful transition is considered attendance in adult care or continued adherence to medication.

We attempted to assess the degree to which each intervention met the standard of the *Got Transition*<sup>24</sup> recommendations. The frequently sparse reporting in the publications made it impossible to be certain whether any of the evaluated intervention programs included each of the *Got Transition*<sup>24</sup> components and we did not feel that we could be certain that a component not reported meant that it was not embedded in the programming.

In addition to the evaluation information on transition care for youth with special health needs that was found in the indexed literature, we catalogued relevant transition care resources, programs, and projects found in the grey literature. We include a detailed list of projects and resources in Appendix C and a summary of ongoing studies and funded projects in Appendix E.

**Figure 1. Literature flow diagram**



## Length of Followup (GQ3b) and Outcomes Measured (GQ3c) in Evaluation Studies

### Diabetes

The most commonly studied group of transitioning youth was diabetic patients (Table 3). Numbers of young people with type I and type II diabetes have been steadily increasing,<sup>149</sup> and some evidence suggests that maintenance of metabolic control may be complicated by hormonal shifts occurring in adolescence.<sup>150, 151</sup> Coupled with the need to participate in an adult health care system, maintaining good control in the transition to adulthood can be challenging in this population.

Interventions studied to date have included use of a transition coordinator (n=3),<sup>113, 117, 122, 145</sup> attendance of the pediatrician at the adult care visit(s) (n=2),<sup>104, 122</sup> education and skill building (n=3),<sup>114, 115, 148</sup> a specialized young adult clinic (n=4),<sup>56, 113-115</sup> and use of technology for education and reminders (n=2).<sup>113, 117, 145</sup> In six models, patients were transferred directly into an adult clinic. Practical assistance with scheduling was used in two programs.<sup>113, 148</sup>

The most common diabetes-related outcomes were HbA1c levels (a marker for glycemic control) diabetes-related hospitalizations, and adult service attendance. . Seven studies used HbA1c levels as outcomes.<sup>56, 104, 113-115, 122, 148</sup> Patient satisfaction was the focus of two studies.<sup>104, 122</sup>

None of the studies was entirely prospective. Five included some sort of comparison group, with three using concurrent comparators, although the analyses were retrospective. Two studies did not use a comparison group at all.<sup>113, 148</sup> In general, studies were published as quality improvement evaluations, rather than with the intention of providing research inferences.

No two studies evaluated precisely the same intervention, although intervention components were common across studies. Nonetheless, there is clearly a need for replicated studies and for the use of concurrent comparison groups to identify best practices. All studies reported either improved health outcomes, or maintenance of health.

**Table 3. Overview of diabetes transition studies**

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
Cadario et. al., 2009 <sup>122</sup> Italy  Retrospective cohort (for identifying cases and collecting clinical data) with cross sectional survey data  1 year	Youth with type I diabetes in structured transfer plan (n=30) or unstructured method (n=32)	Structured transfer plan, including a designated pediatrician transition coordinator working with an endocrinologist to transfer care	Hospital  Adult physicians, transition coordinator and endocrinologist	Date of first admission, mean HbA1c, clinic attendance rates, transition experience	Patients in the structured program had shorter transition, better clinic attendance and lower HbA1c. All reported favorable experience
Gholap et al., 2006 <sup>115</sup> U.K.  Retrospective comparison with data from another published study	Adolescents and young adults ages 16 to 25 with type I diabetes (n=68)	Young person's diabetes clinic that met monthly. Based on the Alphabet strategy, a mnemonic based approach to care:	Outpatient diabetes clinic  Diabetologist, pediatrician, 2 "associate specialists", a	Clinic attendance, HbA1c, hypertension, nephropathy, retinopathy, presence of	Patients who attended young person clinic had lower non- attendance (12% vs. 24.6%), lower mean

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
NR		Advice; Blood Pressure lowering; Cholesterol and creatinine control; Diabetes control; Eye examination; Foot examination; use of Guardian drugs	pediatric and adult nurse specialist, a dietitian and Asian link worker	complications	HbA1c (8.4% vs. 9.5%), better blood pressure monitoring (100% vs. 88%), higher rates of screening for nephropathy, and lower rates of nephropathy (5% vs. 21%) compared with data from a recently published multicenter study.
Holmes-Walker et al., 2007 <sup>113</sup> Australia  Quality improvement assessment included retrospective collection of clinical data 12 months prior to participation and prospective data collection after clinic attendance. No comparison group.  NR	Young adults with type I diabetes aged 15-25 years (n=191)	Transition coordinator or diabetes educator scheduled appointments for young people and provided reminders via phone, email or text; afterhours phone service was available	Young adult diabetes clinic within an adult referral hospital  Diabetes educator	Frequency of clinic visits, HbA1c, diabetic ketoacidosis, admissions	HbA1c improved significantly after a median of 5 visits (p<0.001); 82% attended clinics in the last 6 months; diabetic ketoacidosis admissions fell by 30%
Kipps et al., 2002 <sup>56</sup> U.K.  Retrospective cohort study of four regions, each of which employed a different transition approach  Up to 2 years after transfer	Individuals with type I diabetes aged older than 18 years (n=229)	Four different transfer procedures at the district level: transfer from pediatric clinic to adult clinic, transfer to a young adult clinic, transfer with introduction to the adult provider prior to transfer, initial move to an adolescent clinic before moving to an adult clinic	4 health districts in the U.K.	Age at transfer, clinic attendance rates, HbA1c	Clinic attendance dropped from 94% two years pre-transfer to 57% two years post transfer. Clinic attendance ranged from 29% to 71% across districts with higher rates among patients who met the adult provider before transfer
Lane et al., 2007 <sup>114</sup> Nebraska, U.S.  Retrospective cohort study comparing outcomes in patients participating in the specialized clinic to patients who directly	Young adults with type I diabetes aged 15 to 25 years seen in young adult clinic (n=96) or in general endocrine	Specialized young adult diabetes clinic including an endocrinologist, 2 nurse educators and 2 dietitians. Services included substantial focus on education as well	University diabetes center	Glycemic control measured via HbA1c	HbA1c levels did not change in either clinic overall. Within the highest tertile of HbA1c, patients in the YAC had the largest decrease

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
entered adult endocrine clinics  3 years	clinic (n=153)	as group classes.  The general endocrine clinic (comparison group) met in the same place and also included a multidisciplinary provider team but without a class and with longer intervals between visits.			
Van Wallegghem et al., 2006 <sup>145</sup> and 2008 <sup>117</sup> Manitoba, Canada  Comparison of two cohorts – a younger group who had used the system, and an older group that had transferred prior to its implementation.  Up to one year after referral to the program	Youth with type I diabetes aged under 18 years who participated in model (n=84) and older group aged 19-25 years who had transitioned without support (n=64)	Systems navigator model, administrative coordinator maintains phone and email contact with patients to identify barriers. Delivery methods include a comprehensive website, a bimonthly newsletter, a drop- in group and educational events	Community clinics, diabetes education resource center	Number of medical and diabetes educator visits, first year loss to follow up, diabetes- related hospitalizations, chronic complications, barriers to care in adult system	40% who did not have access to the navigator dropped out of medical care versus 11% who did
Vanelli et al., 2004 <sup>104</sup>  Cross sectional survey of patient experience, with pre- transition and post- transition HbA1c data collected from medical records. No comparison group.  One year post transition and at study initiation	Adolescents with type I diabetes (n=73) with a mean age at transition of 21.0±0.95 years	Protocol for an uninterrupted procedure for transfer including introduction to the adult provider prior to transition and attendance by the pediatrician at the first adult visit. Transition occurred when the patient and parents agreed	Pediatric, adult specialty clinic  Pediatric and adult providers	Patient satisfaction, attendance, HbA1c	94% of patients reported being satisfied with the process. Consensus about readiness to transition was achieved within 2 to 4 visits for 66% of patients. Mean HbA1c one-year post transition was 7.6±1.1% compared to 8.8±2.1% pre- transition
Vidal et al., 2004 <sup>148</sup>  Pre-post, no comparison group  1 year	Young adults with type I diabetes and a mean age of 19±1.3 years at transition (n=80)	Therapeutic Education Program (TEP) for young adults transferring to adult care, including coordinated transfer visits, initial extended evaluation by adult staff (90 minutes), a	Hospital-based adult outpatient clinic  Adult endocrinologist and nurse; 12 to 15 hours dedicated to each patient,	Meal plan composition, total daily insulin, HbA1c, body weight, number of hypoglycemic episodes	No changes in meal plan composition, no differences in daily insulin dose, increase in proportion of patients performing readjustments of insulin dose,

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
		pact to commit to the insulin therapy protocol with goal-setting, 4 group sessions with relatives, 3 to 6 individual visits over 6 months	half of which were in group sessions		decrease in HbA1c and in the number of hypoglycemic episodes

Abbreviations: HbA1c= Glycosylated hemoglobin; U.K.=United Kingdom; U.S.=United States

## Solid Organ Transplant

A small body of literature<sup>13, 68, 121, 123, 141</sup> is available on the transition of pediatric patients with organ transplants to adult care (Table 4). Four of the five studies focus on kidney transplant patients, with the remaining study on liver transplant. All of the studies on kidney transplant patients include the evaluation of a specific transition oriented clinic – either one for youth alone, or a joint pediatric-adult clinic. The one study on liver transplant patients evaluated the role of a transition coordinator.<sup>123</sup> This was the only prospective study, but the study did not use a concurrent control group, relying on historical comparators who had transitioned prior to implementation of the coordinator role. The four studies on kidney transplant patients report clinical outcomes, including organ rejection and mortality. The study on liver transplant patients reports on patient satisfaction and psychological benefits, in addition to medication adherence, which is confirmed via blood draw.

**Table 4. Overview of transplant transition studies**

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
Annunziato et al., 2013 <sup>123</sup> U.S.  Prospective evaluation using historical (asynchronous) comparators who transferred prior to establishment of a transition coordinator  1 year	Patients in the pediatric liver transplant program (n=20) and historical cohort (n=14)	Transition coordinator who assisted with preparation, served as a liaison between pediatric and adult services, provided care coordination, provided outreach before and after transfer, and implemented research protocols to evaluate transition programming	Academic medical center; transition coordinator was a licensed clinical psychologist	Medication adherence measured via patient report and blood levels; Psychosocial outcomes including developmental skills and acceptability of the transfer process	Medication adherence was significantly better for patients who had access to the transition coordinator compared with the cohort who did not
Chaturvedi et al., 2009 <sup>121</sup> Australia	Pediatric kidney transplant	Transition clinic, development of self-	Children's hospital renal clinic	Serum creatinine levels, episodes of acute rejection,	Patient health outcomes were fairly stable

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
Retrospective review of case notes followed by a patient survey  12 months	recipients (n=11)	management skills and a written transition summary	Transition coordinator, transition adult nephrologist, and transition nurse	number of inpatient days, frequency of scheduled appointments and missed appointments	during the 12 months before and 12 months following transfer as measured by number of acute rejection episodes and hospital inpatient days. Adherence, as measured by attendance of scheduled appointments dropped from 73% before transfer to 57% after transfer
Harden et al., 2012 <sup>141</sup> U.K.  Comparison of two cohorts – a younger group who had used the system, and an older group that had transferred prior to its implementation  Between 1 and 60 months after transfer	Young adult kidney transplant recipients (n=21); before 2006 (n=9); between 2006 and 2010 (n=12)	Integrated pediatric-young adult joint transition clinic and care pathway plus a young adult clinic located in a college sports center that included a youth worker.  Patients are seen jointly by pediatric and adult teams from ages 15 – 18 and then transfer to the adult clinic at age 18. Patients are seen by providers without family members present to promote autonomy, and then meet with family members to review progress and management plans	Adult renal center and two pediatric renal centers	Rates of acute organ rejection, morbidity, admissions	Six of nine patients who transitioned before implementation of the transition clinic had transplant failure compared to no transplant failures in the group that transferred after implementation of the transition clinic
Pape et al., 2013 <sup>13</sup> Germany	Pediatric kidney	Specialized transition clinic	Academic medical center	Survival, stability of	There was no difference in

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
Retrospective cohort  One year prior and one year after transfer	transplant patients (n=66) in a transition clinic (n=15), patients transferred directly to an adult nephrologist (n=25), patients attending an adult nephrology clinic with a phase of alternate appointments over 1 to 2 years before transfer	led by a specialized adult neurologist		immunosuppressive therapy, use of steroids and patient satisfaction	changes in clinical outcomes before and after transfer between the settings. Patient satisfaction was higher among those who transitioned via a specialized adolescent clinic compared with the patients who transferred to an adult nephrologist, either directly or by alternating appointments
Prestidge et al., 2012 <sup>68</sup> Canada  System-level pre-post using historical controls  2 years	Kidney transplant recipients pre- transition clinic (n=34); transferred after opening transition clinic (n=12)	Multidisciplinary transition clinic where patients are seen every 4 to 6 months until transition in addition to attending standard transplant clinic. Each patient is seen individually by the team members listed to the right. Specific educational goals include identifying the primary care provider, demonstrating medication knowledge, recognizing signs of rejection and infection, appraisal of ability to self- manage and awareness of reproductive health issues	Children's hospital, which is the referral center for renal transplantation in the region. Team includes a dedicated pediatric nephrologist, renal nurse, youth health specialist, renal pharmacist, renal dietician and social worker.	Deaths, allograft losses, graft function, costs per patient	The time to either graft loss or death was better for individuals transferred to adult care after implementation of the transition clinic than for individuals who transferred to adult care prior to implementation of the transition clinic. The average annual cost was less per patient for those who participated in the transition care clinic

**Abbreviations:** U.K.=United Kingdom; U.S.=United States

## Other Conditions

We identified an additional eight studies<sup>88, 102, 103, 124, 142, 143, 146, 147</sup> on a range of conditions (Table 5), with no two studies on the same condition. Two studies included patients with a variety of conditions,<sup>88, 146</sup> while the remainder of the studies had one clinical focus. Two programs used a transition coordinator.<sup>102, 124, 144</sup> Two programs used multidisciplinary teams to provide care jointly,<sup>102, 146</sup> and one evaluated a separate young adult clinic.<sup>103</sup> One program provided direct scheduling of visits,<sup>147</sup> and one was a mentoring group that met over 10 months.<sup>88</sup>

**Table 5. Overview of other special health needs transition studies**

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
Bent et al., 2002 <sup>146</sup> U.K.  Cross sectional  NA	Youth with longterm physical disability (n=245)	Young Adult Teams, including multidisciplinary teams including a consultant in rehabilitation medicine, a psychologist, therapists and a social worker	4 health care regions in the U.K., 2 with YAT services and 2 with ad hoc services	Participation in society based on the international classification of functioning, disability and health (ICF)	Individuals in the Young Adult Teams were more likely to participate in society than individuals who used ad hoc services
Bundock et al., 2011 <sup>142</sup> U.K. and Australia  Comparison of satisfaction with transition care among youth with HIV compared to youth with diabetes  NR	Adolescents with perinatally acquired HIV in (n=21); Adolescents attending diabetes transition service (n=39)	Outpatient services using sequential approach to transition for HIV patients  Outpatient clinic using direct transition model for patients with DM	Academic health science center clinic  Pediatric infectious disease specialist, adult senior lecturer in HIV genitourinary medicine, adult HIV clinical nurse, adult psychologist	Patient satisfaction	Patients in both groups reported that transition from pediatric to adult care went smoothly and that transition was associated with improved health care
Chaudhry et al., 2013 <sup>102</sup> Michigan, U.S.  Retrospective survey  NA	Adults with cystic fibrosis (n=91) in a transition program vs. non-program participants	Structured transition program beginning early in adolescence, focusing on developing independence. Included a transition coordinator and participation of the adult pulmonologist in the pediatric clinic until readiness is achieved	Academic medical center	Patient satisfaction, perceived health status	Patient who went through a transition program were more satisfied with care before transferring to adult care
Gleeson et al.,	Individuals	Young Person	Children's	Adult clinic	Introduction of the

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
2013 <sup>103</sup> U.K.  Retrospective record review  NA	with congenital adrenal hyperplasia aged 16 years and older who attended pediatric clinic from 1992 to 2009 (n=61); pediatric clinics (n=37); Young Person Clinic (n=24)	Clinic (YPC) at which the youth is introduced to an adult endocrinologist	hospital  Young Person Clinic had both pediatric and adult endocrine teams in attendance	attendance	Young Person Clinic had no effect on rates of engagement, with 50% lost to followup after transfer to adult services
Hankins et al., 2012 <sup>147</sup> Tennessee, U.S.  Pre-post pilot study  18 months preceding start of transition program and 18 months after start of the transition program	Youth with sickle cell disease aged 17 to 19 years (n=83)	Transition Pilot Program including a tour of adult SCD programs, lunch discussion with pediatric staff and scheduling of the first adult visit by the pediatric hematology case manager	Pediatric hospital  Pediatric hematology staff	Proportion of pediatric patients fulfilling their first adult hematology appointment	Most (74%) of the transition program participants completed their first adult hematology appointment within 3 months as compared to 33% of those who did not participate in the transition program
Jurasek et al., 2010 <sup>143</sup> Canada  Cross sectional  NA	Adolescents with epilepsy (n=97)	Nurse-led Adolescent Epilepsy Transition Clinic	Children's hospital	Patient satisfaction, understanding, and fears at 2 to 3 months after first visit	Patients and caregivers were satisfied with the transition process
Maslow et al., 2012 <sup>88</sup> Rhode Island, U.S.  Pre-post  Length of time from pre- to post-test varied from 3 to 10 months  One or more years following program participation (mean age of 20.6 years)	Individuals with a chronic illness (14 different conditions) aged 13 to 19 years (mean age 15.4 years) (n=20)	The Adolescent Leadership Council (TALC)  10-month group mentoring program based on the Positive Youth Development framework	Children's hospital  Pediatric and psychiatry residents, child life therapists, medical students, supervised by pediatric and psychiatry attending physicians; Had a fulltime director and clinical care was provided pro bono	Loneliness, chronic disease management, self-advocacy and successful transfer to adult care	Participants reported less loneliness and improved self-advocacy after participation in the mentoring program.  There was a small increase in transition readiness scores for program participants
McDonough et al., 2006 <sup>124</sup> and Shaw et	Adolescents with juvenile	Program of transitional care	10 pediatric rheumatology	Satisfaction with care,	Overall satisfaction scores improved

Citation Location Study Description Length of Followup	Population	Model	Setting(s)/ Provider(s)	Outcome(s) Reported	Results
al., 2006 <sup>144</sup> U.K.  Systems-level pre- post  12 months after clinic visit	idiopathic arthritis aged 11 to 18 years (n=308)	coordinated within each center with a program coordinator funded for one day per week. Patients worked through a series of templates that were developmentally appropriate and focused on home, health, and school. Informational resources were provided to patients and their families.	centers	health-related quality of life, and arthritis- related knowledge	significantly for adolescents and their parents after transition program implementation

**Abbreviations:** NA=not applicable; NR=not reported; U.K.=United Kingdom

## Guiding Question 4. Issues and future research

- w. What are the implications (e.g., ethical, privacy, economic) of the current level of diffusion and of further diffusion of transition care for children/adolescents with special health care needs?
- x. What are possible areas of future research for transition care for children/adolescents with special health care needs and which research designs are most appropriate to address these research topics?

## Implications (GQ4a)

Documented decreases in adherence to medications and clinic appointments following transition are important reasons to maximize successful transition.<sup>70, 138</sup> Decreases in adherence are associated with worsening clinical outcomes including increased hospitalizations secondary to poorly controlled diabetes<sup>70</sup> and increased allograft loss in kidney transplant recipients<sup>138</sup> following transition, suggesting that the risks of unsuccessful transition are significant and that a paucity of transition programs could have substantial implications.

Poor reimbursement for transition services affects the ability of clinics to provide this care, which is often time intensive and multidisciplinary.<sup>152, 153</sup> Up to 70 percent of physicians have reported that compensation adversely affected their ability to provide appropriate care for children with special health care needs due to lack of time, lack of patient insurance coverage and low reimbursement for the extra time required.<sup>153</sup> One review identified billing codes that can be used by clinicians to obtain appropriate reimbursement for these services, but it is unclear whether many or most physicians and coders are aware of how to use these codes appropriately.<sup>154</sup>

Given poor reimbursement and an overall dearth of transition programs, the reach and success of interventions may be affected by the income of the patient's family or type of insurance<sup>108, 152</sup> as access to medical care in the adult system is often limited for those patients with Medicaid insurance coverage.<sup>119</sup> Historically, the adolescent and young adult years marked

a time during which a child was no longer covered under a parent's insurance.<sup>155</sup> This impact may be minimized in future years by the implementation of the Affordable Care Act. Inequality exists in overall access to health care in the adult clinical setting with those of lower income or without private insurance receiving less access to health care, which affects medical care post-transition.<sup>156</sup>

Racial disparity may also occur, with some research suggesting that transition from pediatric to adult care is less successful in non-Hispanic black and Hispanic patients compared with Caucasian patients<sup>108</sup> and less successful in minority patients in general compared with Caucasians even in the setting of the pediatric medical home.<sup>152</sup> In addition, a higher familial education level has been associated with more successful transition, which may imply a lack of health literacy in the lower educated families whose educational needs are not met in the current transition systems.<sup>152</sup>

One barrier to successful transition is the lack of experience and training of adult clinicians in chronic diseases that were historically pediatric diseases.<sup>34, 49, 54, 157</sup> In addition to the lack of experience of the clinicians, many adult clinics are not designed to treat adults with behavioral or developmental concerns, raising valid ethical concerns about whether it is even appropriate to transition those patients to an adult provider unprepared to care for them.<sup>119</sup>

There are particular risks for patients with developmental or cognitive delay in that the current transition process most often involves an adult clinic, which has more of an individual focus rather than family focus when the patient's needs may require family-focused care.<sup>49, 119, 158</sup> Integrated systems of support for multidisciplinary care that are available in many pediatric practices are often not present in the adult clinic setting, creating unmet need in this patient group.<sup>54, 146, 156, 159</sup>

Finally, there is the question of privacy as more providers and types of providers have access to the patient's medical information, and this should be addressed in the development of any transition program.<sup>34, 159, 160</sup>

In sum, the implications of the current diffusion of transition care are that many young people who need support in moving from pediatric to adult care are not receiving that support, and the adult system of care is unprepared to receive them. The risk of these patients falling through the cracks is substantial as they have serious and ongoing medical needs.

## **Areas for Future Research (GQ4b)**

Methodologic and substantive issues should be addressed in future research about transition care. Methods issues include a common and validated definition of transition success, a need for more rigorous study designs, more funding, and inclusion of a broader range of clinical research perspectives. Areas and opportunities for future research include: technology, disease progression, educational research, and cost effectiveness research.

## **Definition of Successful Transition**

A major barrier to transition research is a lack of well-defined outcome measures.<sup>75, 80, 161, 162</sup> Possible metrics to evaluate success could include perceptions of success and satisfaction with the transition process (clinician's, adolescent's, parent's), improved or stable disease-specific medical outcomes,<sup>118, 159</sup> decreased or stable cost of medical care, or educational milestones in a patient's ability to care for themselves or navigate the medical setting.<sup>98, 163, 164</sup> Without clear clinical or functional outcomes identified, most studies have focused on qualitative measures including clinicians' or patients' perceptions of success without objective measurements to

support the claims of success of individual transition programs. No validated measures of transition have been developed.<sup>161</sup>

Future methodologic research should focus on identifying or developing objective measures of successful transition as well as transition tools.<sup>83, 112</sup> Quality of life and personalized outcomes identified by the adolescents participating in transition programs could be significant outcome measures, but others should be developed as well.<sup>75, 156, 161, 162, 165</sup> In addition, very few studies provided data on long-term followup, which could be important for considering the ultimate success of transitioning.

## **Study Design**

Randomization in transition research can be problematic as medical care is multidisciplinary, and isolating any one intervention or holding constant concomitant interventions, even in a randomized controlled trial is difficult.<sup>119, 123, 146, 163</sup> However, rigorous evaluation of these multidisciplinary transition programs is still needed. In addition, transition is a long process often beginning in early adolescence and continuing through young adulthood, and ideally studies would include evaluations of subjects before, during and after the transition period. These studies would therefore need to be longitudinal and fairly long, and thus may be cost prohibitive.<sup>91, 120, 162, 163</sup> One method to obtain prospective data for evaluation of programs would be the development of disease-specific or location-specific core transition data sets which could be used for research of the transition process over the short term period as well as longitudinally.<sup>163</sup>

One alternative method to longitudinal evaluations of the impact of transition on patient outcomes and to overall improve the transition process is utilization of quality improvement initiatives and processes and quality improvement evaluation designs.<sup>57</sup> Quality improvement research could help identify best practices for transition,<sup>57</sup> factors within transition that affect outcomes positively or negatively,<sup>98, 118, 162</sup> as well as individual predictors for successful transition.<sup>118, 162</sup>

## **Funding**

Funding streams generally focus on specific diseases, but the field of transition research would benefit from more generalized research that can identify effective methods across disease groups. Identifying funding streams that are non-disease specific may be challenging but important.<sup>163</sup>

## **Involvement of Pediatric and Adult Researchers**

Traditionally, transition efforts and transition research has been led by pediatric providers even though adult providers are an essential component to the transition process. Future research should include both pediatric and adult researchers.<sup>163</sup>

## **Technology**

The use of technology in transition has particular promise for adolescents, who tend to be comfortable users of technology. Novel uses of technology to improve adherence to medications, to provide education regarding their medical disease, to identify medical deterioration earlier, and to communicate with their medical providers should be considered in future studies.<sup>80, 163, 166</sup> One study reported improvement in medication adherence and decreased rejection in pediatric liver transplant patients who received text message reminders, but more research is needed in the area to confirm and expand on this concept.<sup>163</sup>

## **System Related Information**

A paucity of data exists regarding how individual systems affect transition. Transition programs would vary based on the healthcare system in which the programs are implemented. Some pediatric and adult programs would share a core electronic medical record whereas other systems function more independently requiring development of standardized methods to communicate the complex medical history of the transitioning patients. While research focusing on generalizable transition care programs is essential, the development of validated tools to aid a variety of systems in implementing successful transition programs is also necessary. Evaluations of transition care programs will need to specify the type of systems in which the transition was performed and what resources or tools were required to implement the program. Documentation of resources could include specific programs such as city based transportation programs available to patients, or clinic and institutional resources such as personnel, educational opportunities, and electronic medical record support.

## **Natural Progression of Diseases**

With improved clinical outcomes, many chronic diseases that were formerly seen only in pediatrics are now affecting adults. The adult course of these diseases is largely unknown, and therefore, aspects of transition specific for these diseases remain unclear. For these diseases, prospective tracking of the natural course and complications of these diseases will be necessary to determine what components of transition will be required when caring for adults with these diseases.<sup>119, 156, 159</sup>

## **Patient Specific Information**

Appropriate timing and necessary tools for successful transition may vary by severity or type of disease. A transition program for individuals with a mildly debilitating disease would focus on disease self-management skills and medical system navigation whereas a transition program for individuals with severe disease may focus on palliative care and end of life challenges. The desired outcomes of the transition programs would vary based on severity of disease as well. Research of these programs would need to control for these differences in care and outcomes.

Cognitive impairment can be associated with some chronic diseases which affect children transitioning to adult care. The severity of cognitive impairment influences the degree with which a young adult can manage their own care and therefore affects measures of successful transition. In addition, physical developmental delays or impairment can affect the ability of individuals to navigate the medical system independently. Successful research in transition would need to include stratification for cognitive ability and developmental delay for the subjects if variability exists. Research efforts to evaluate the success of transition program modifications for patients with cognitive or physical impairments are needed.

## **Educational Research**

As transition programs progress, one area of research that will be important is educational research to determine whether adult providers, multidisciplinary team members, adolescent providers, and developmental medicine providers are trained in the tenets of successful transition for adolescents with special health care needs.<sup>167</sup> Educational research can also focus on the education provided to patients and parents throughout the transition process.<sup>48, 72, 91, 110</sup>

## **Cost Effectiveness Research**

Only one cost study was identified, and it took place in England so may not be relevant to the United States health care system. The study did identify increased costs associated with the transition period, but did not find that an organized transition program was more resource intensive than ad hoc services.<sup>146</sup> Cost effectiveness of transition programs compared with the cost of unsuccessful transition of this patient population is an area in which research should be conducted.<sup>123, 165</sup>

## Summary and Implications

The issue of how to provide good transition care for children with special health care needs warrants further attention. The numbers of children with special health care needs reaching adulthood are increasing, and the diversity of their clinical conditions is expanding. The *Got Transition*<sup>24</sup> resource provides a framework for transition care that can be adapted to serve the individual needs of a given patient population, but there is little evidence that it is used to provide a framework for evaluation in the research literature. Despite identifying numerous descriptions of existing transition programs or services, we identified only 21 evaluation studies, the majority of which did not include concurrent comparison groups. Most (n=8) were conducted in populations with diabetes, with a small literature (n=5) on transplant patients and no more than one study on each of a number of other conditions. Common components of care included use of a transition coordinator, a special clinical for young adults in transition and provision of educational materials, sometimes using computer-based programming.

An important consideration going forward is recognizing that transition care for chronic conditions like diabetes may warrant a different approach than care provided for more heterogeneous and complex conditions, particularly those that include a behavioral or intellectual component. Care for some patients may be appropriately provided in primary care at the community level, while for others, it may be appropriately provided only in highly specialized regional or academic centers.

Research needs are wide-ranging, including both substantive and methodologic concerns. At this point in time, the field lacks even a consistent and accepted way of measuring transition success, and it will be essential to establish consistent goals in order to build an adequate body of literature to affect practice.

## Next Steps

The issue of how to provide good transition care for children with special health care needs warrants further attention. The numbers of children with special health care needs reaching adulthood are increasing, and the diversity of their clinical conditions is expanding. An important consideration going forward is recognizing that transition care for chronic conditions like diabetes may warrant a different approach than care provided for more heterogeneous and complex conditions, particularly those that include a behavioral or intellectual component. Care for some patients may be appropriately provided in primary care at the community level, while for others, it may be appropriately provided only in highly specialized regional or academic centers.

Research needs are wide-ranging, including both substantive and methodologic concerns. At this point in time, the field lacks even a consistent and accepted way of measuring transition success, and it will be essential to establish consistent goals in order to build an adequate body of literature to affect practice. As noted in our brief, although the *Got Transition*<sup>24</sup> principles are described by experts as the ideal basis for transition care, intervention studies are reported in such a way that we were unable to track back their interventions to these principles. If investigators would at minimum describe their interventions with the *Got Transition*<sup>24</sup> rubric – or another agreed upon rubric – then synthesizing the literature as it evolves would be more straightforward and enhance applicability. Research on the costs and resources needed to provide good care will improve the likelihood of diffusion, and may provide a basis for understanding reimbursement challenges, and the broad availability of tools and materials to support providers and teams have the potential to reduce costs and increase provision of care.

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